



18TH EHEALTH NETWORK 12-13 NOVEMBER 2020, BRUSSELS, BELGIUM

COVER NOTE

10.2 D5.3 Paper on common principles for big data governance – eHAction

1. Issue at stake

The focus is on raising awareness with patients and policy makers on the use of big data in healthcare. It needs to be transparent to patients and healthcare professionals on how, when and for which purpose their data is being used.

The main objective of the work package 5 (WP5) on innovative use of the health data is to support application of good practices in Member States/countries. Provide recommendations how to handle big data in health within the existing EU regulatory framework on secondary use of health data, and consequently to ease the uptake of innovative usage of data across the healthcare sector for the benefits of society, individuals and performance of Member States health systems.

2. Summary

This document includes deliverable 5.3 (D5.3): Draft proposal for the eHealth Network – Guidance for the implementation of common principles for practical governance of big data with a special focus on data to be used (and the implementation of data access and use) in public health, research and quality assurance in healthcare on a European scale.

The draft proposal provides information about the background, objectives, planned structure, working definitions and methods of D5.3, and contains recommendations on common principles for practical governance of big data.

The deliverable D5.3 is developed based on the outcomes received from the other two deliverables of the WP5: D5.2 on identified cross-border use cases and practical solutions with potential for European scale benefits (adopted in the 16th eHealth Network meeting in November 2019); and D5.1 on policy-level actions on innovative use of big data in health (adopted in the 17th eHealth Network meeting in June 2020).

The main findings of WP5 deliverables D5.1 and D5.2, a series of challenges and obstacles were identified. These are: lack of trust, gaps in the legal environment or uncertainties how to apply legal provisions, the level of digital literacy, lack of business models, interoperability issues, confidentiality issues, safety of health data, privacy, cybersecurity, intellectual property issues, unsolved issues of sharing benefits among stakeholders, and scarce resources including the number of data scientists. It is important that these hurdles should be solved or dealt with before the aim to create a European healthcare data space.

3. Format of procedure in the meeting

For discussion.